

GUIDE TO SUCCESS:

Navigating Montana's Developmental Disabilities Program

*A GUIDE TO UNDERSTANDING THE
DEVELOPMENTAL DISABILITY SERVICES SYSTEM.*



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A Publication of



Montana's Parent Center

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DISABILITY SERVICES SYSTEM**

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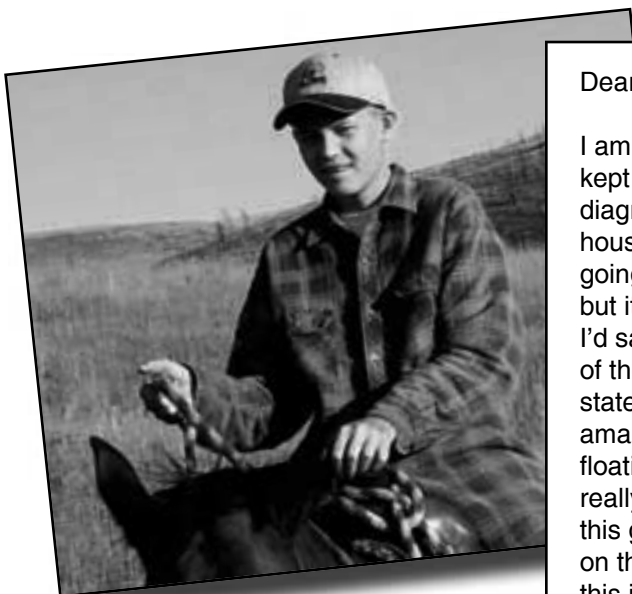
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To download the electronic version of this guide, and view other resources, please visit:
<http://www.pluk.org/ddpguide>

Letters from Jeff Sturm (DDP Director) and Dianne Booth (parent):



Dear parents/readers,

I am one of the parents who worked on writing this guide. We kept thinking of what we went through when our kids were first diagnosed and then how these people started showing up at our houses. No one really explained what was happening or what was going to happen. They were nice people, and they did good things, but it was confusing. Asking for help and receiving it was also hard. I'd say we parents that worked on this really had no understanding of the DDP system until we got together with the folks at the state office to talk about putting this guide together. That was an amazing day. We were able to ask these questions that had been floating around in the back of our minds all these years. A picture really came together in my head that day, and that is what I wanted this guide to do for other parents, especially those just beginning on this road. I am proud of what we have done and know that this is going to help you. This guide isn't about all the laws and regulations, but it does give enough information so you can track down information about any question you might have. We'll never be able to know all the details, but I know who to call, and with this guide, so will you.

And this is just a start. We want to get parents and everyone's feedback on this. We want to have more information on a web site and post updates and an electronic version that anyone can print. The other thing that I learned is that we need to be involved and connect with other families. The people that make the decisions need to hear from us so they can be smarter. They can make us smarter too, and show us how the system can be changed. When we work together, we can make those changes that will help our kids. That's one of my jobs now along with the rest. I'm putting my e-mail address here. Just let me know if you want to help.

Dianne, mother to Logan (pictured)
primrose@mtintouch.net

Dear self-advocates and families,

Over the past several years, the Developmental Disabilities Program has gone through many changes. The changes happened for many reasons and, at times, seem pretty confusing. This guide is an attempt to help you understand the Developmental Disabilities Program service system so you can better access services for yourself or your family member. The guide contains information that should make things less confusing or where to go for questions.

The Developmental Disability systems in Montana and across the country are changing constantly due to the different needs of individuals in services, their families, funding, as well as changes in national and state policy. As a result, this guide will be updated as those changes occur.

Our goal is to make sure that families and individuals receiving services not only understand what services and options are available but also act as our partners in designing the system for the future. Please share your thoughts, ideas and concerns with us so we can provide a service system that truly meets your needs.

Thank you,

Jeff Sturm
Developmental Disabilities Program Director, Helena



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Introduction

In Montana's Developmental Disabilities Program, services are available at no cost to eligible individuals of any age. There are many kinds of services available. Currently, there are two ways to access these services: through community-based providers, and through self-direction. We will explain these options later. You need to know enough about these options to choose which ones are best for you. You will also want to know who provides the services, how they do business, who works for them, how their values fit with yours, and how you can best use their services. Don't be afraid to ask lots of questions!

1. What are Developmental Disability Services?



All parents grow with their children, and parents of individuals with developmental disabilities are no different. For much of what a child needs, family is the BEST resource. Still, there may come a time when additional support from people outside the family would make all the difference in the world. That extra support comes through the

Developmental Disabilities Program and is referred to as “services”.

You will need to understand how the Developmental Disability Program (DDP) eligibility process works, as well as how to get services. But don't worry, eventually you'll become familiar with the terms and language, and learn how to build successful relationships with community-based service providers.

We know that Montana's DDP operates in a maze of regulations which are difficult to understand. It's no wonder -- the **Developmental Disabilities Program (DDP)** currently has a budget of \$114 million and serves over 4,000 individuals.

This Success Guide was written for and by parents and self-advocates to help you understand what DDP's services are and how these services can work for you. That's why we've organized our guide in a way that will help you begin your journey.

It is important to understand that all of the programs described in this guide were created to help people with developmental disabilities. Even though navigating this system can sometimes be difficult, remember that you're not alone. Many families may have the same questions that you have, and communicating with other parents and professionals within DDP and the community will help create a strong support system.

2. What is a Developmental Disability?

The word “disability” has different meanings for different people. For some, the word suggests a specific medical condition, while others think of how well a person can perform the everyday tasks of living.

A **Developmental Disability** is a documented delay in cognitive or behavioral function compared to others in the person's age group.

The **Developmental Disabilities Program (DDP)** is a program within the larger DPHHS agency. DDP administers, provides funding, processes payments, and monitors all the different services that are offered through DDP.

Below is the official definition, from Montana State law, of developmental disability that is used by Montana's DDP to decide if someone is eligible for services:

A developmental disability is a disability attributed to mental retardation, cerebral palsy, epilepsy, autism or other neurological handicapping condition closely related to mental retardation and requiring treatment similar to that required by individuals with mental retardation* if the disability originated before the person attained age 18, has continued or can be expected to continue indefinitely, and constitutes a substantial handicap to the person.**

*Though the state definition uses the term "mental retardation", in this guide, we will use "intellectual disabilities"

Children or adults with developmental disabilities are often able to do many things that others can do -- they just need some extra help. Most of this help is provided by families, but sometimes there are situations where more assistance and training is needed than the family can provide. One option for this additional support may be DDP.

3. What is the Developmental Disability Program (DDP)?



The Department of Public Health and Human Services (DPHHS) is a large, state-run agency that is in charge of many programs, including Medicaid, Public Health and Safety, Public Assistance, Children's Mental Health, and the Developmental Disabilities Program (DDP).

DDP provides oversight and funding for the service system that supports individuals with developmental disabilities and their families. They currently have an annual budget of \$114 million, serve over 4,000 individuals and work with over 60 service providers across Montana. The mission of the Developmental Disabilities Program is to ensure choices and opportunities for people with developmental disabilities in their communities.

Department of Public Health and Human Services (DPHHS) is a large, state-run agency that is in charge of many programs, including Medicaid, Public Health and Safety, Public Assistance, Children's Mental Health, and the Developmental Disabilities Program (DDP).



4. Where is DDP Located?

The Developmental Disabilities Program has one central office in Helena with five regional offices throughout Montana. You may contact your regional office for unbiased information about services and providers at any time.


Central DDP Office:

111 Sanders, Room 305
PO Box 4210
Helena, MT 59604
(406) 444-2995
(406) 444-0230 FAX


Region III DDP Office:

2121 Rosebud Drive Suite C-1
Billings, MT 59102
(406) 259-8122
(406) 652-1895 FAX

III
Region I DDP Office:

226 6th Street South
PO Box 472
Glasgow, MT 59230
(406) 228-8264
(406) 228-8263 FAX

I
Region IV DDP Office:

PO Box 202955
3075 North Montana Room 108
Helena, MT 59620
(406) 444-1714
(406) 444-0826 FAX

IV
Region II DDP Office:

201 First Street South Suite #3
Great Falls, MT 59405
(406) 454-6085
(406) 454-6082 FAX

II
Region V DDP Office:

2675 Palmer, Suite B
Missoula, MT 59801
(406) 329-5415
(406) 329-5490 FAX

V

5. What is Eligibility?

Before services can be received, a person must first be found “**eligible for services**”. Being eligible for DDP services means that a person of any age with an intellectual or cognitive disability (diagnosed before age 18) has been found to have a significant level of difficulty doing things that are important to everyday life.

It is important to note that there are different services offered for different age groups (e.g: infant, child, youth or adult). You can get more information about what services are available from your local regional office.

It is also important to understand that the eligibility criteria used for DDP services are separate from the services you or your family member may receive through your school district, **personal insurance** (see page 15), Medicaid, Social Security, or other sources (such as **Healthy Montana Kids** and **Montana Comprehensive Health Association**). For example, you do not have to be eligible for DDP services in order to receive school services (or vice versa).

6. How is Eligibility Determined?

If you think you or a family member may be eligible for services and supports, contact the DDP office in your region. Your doctor, school, or someone else involved with your child may also suggest you contact DDP.



The regional DDP office will either help you apply for services directly or refer you to a provider agency that can help you fill out an application.

The eligibility process will look at the assistance you or your family member needs. This may involve having several different people in your home to make evaluations and ask questions. You may also need to submit doctors' reports/evaluations, hospital records, school

district evaluations, or other documentation to determine if the disability meets the requirements set by the state for eligibility.

After submitting the application and documentation, you will receive notification of eligibility for disability services through DDP.

If you are not considered eligible, you may appeal the decision. The letter regarding eligibility will explain how the appeals process works.

Eligible for services means that a person of any age with an intellectual or cognitive disability (diagnosed before age 18) has been found to have a level of difficulty doing things that are important to everyday life, and may receive DDP services.

Personal Insurance (Autism)

The Montana Autism Reform Law requires many private insurers to begin covering the costs of diagnostic assessments for autism and of treatments for individuals with autism through:

1. \$50,000 per year for a child 8 years or younger
2. \$20,000 per year for a child 9 years through 18

The specific terms and provisions of this law are described in more detail at: <http://www.pluk.org/autismvotes>

Healthy Montana Kids is a free or low-cost health coverage plan. The plan provides health coverage to eligible Montana children and teenagers up to age 19. More information can be found at: <http://hmk.mt.gov/>

Montana Comprehensive Health Association is a program that offers policies of individual health insurance to eligible Montana residents who are considered uninsurable due to medical conditions. It is not intended to duplicate coverage from any other source, public or private. More information can be found at: <http://www.mthealth.org/>

7. What is the Wait List, Eligibility and Services?

If you are determined eligible for services, you may be placed on a wait list (Except for eligible children under 36 months, who should immediately receive Part C services. See page 8). This happens because there are more people needing services than there are funds available. It can take anywhere from a few months to a couple of years or more to get selected for the service(s)



you need. Developmental Disability (DDP) services are available based on funding provided by the state legislature (state general fund) and federal funding (Medicaid). Don't forget that you may call your regional office at any time to check your status on the wait list.

Once you are selected for services, you will be notified and given a list of provider agencies in your community, as well as a list of the services each one is qualified to provide. Before selecting an agency, it's a good idea to visit, meet with staff, and talk to other families to see which is the best match for you. Once you have selected a service provider (or providers), they will help you develop your support plan (a list of services you need). Keep in mind that you do not have to select all of your services through one provider. For example, you may use day services from one provider, and respite from another. The choice is yours.

In addition, there is a new service option available called self-directed services. This means the individual or family directs the service and manages the cost plan with help from a fiscal agent. More and more services are being offered with the self-direction option. Contact your case manager or regional office for more information.

As always, you may contact your regional office for unbiased information about services and providers at any time.

8. What are Community Providers?

In order to coordinate services to individuals and families, the Developmental Disabilities Program contracts with providers across the state of Montana. In larger communities, you may have several agencies to select your services from, while many smaller communities only have one or two providers to choose. Before you decide on a service provider, you may want to talk with other individuals and families who already use their service(s). For more details of provider agencies in your area, and the services they are qualified to provide, call your regional office.

9. What is the Montana Developmental Center?

The Montana Developmental Center (MDC) in Boulder, Montana serves individuals, 18 and older, who are determined to be a danger to self or others and in need of more intense treatment. Placement is made through a court process when services in the community cannot safely meet the individual's needs.

10. What are Support Plans?

As we touched on before, when you or a family member has chosen your provider(s), a support plan will be written. A team with members of your (or a guardian's) choice will work to develop the plan based on suggestions from team members and the assessment of needs.

Services vary depending on the age of the individual with the disability. For those receiving children's services, support is provided through a plan called an **Individualized Family Support Plan (IFSP)** which supports both the child and the family. For example, children's services may include respite (a break for unpaid caregivers), assistance with household responsibilities, caregiver training and support (education and training for the family) that is focused on the needs of the child/family.



For those receiving adult services, the plan will be tailored to the individual needs of the person being served through a **Personal Support Plan (PSP)**. Services are community-based and can usually be provided near the area where the individual lives. Services may include assistance with transportation to shop, work, or attend community activities, as well as help with budgeting or paying

bills, and providing a job coach or respite for caregivers. In short, services provided are designed to promote independence and focus on the health and safety of the individual being served.

Finally, for those receiving waiver services (either children or adults), a budget, or **Individual Cost Plan (ICP)**, is created with the assistance of a case manager to distribute the funds that carry out the support plan. These funds may be portable, which means they can be moved to other providers and services at any time in order to meet the needs of the individual. These changes are made through the support plan.

Individualized Family Support Plan (IFSP) is a support plan for a person under age 18 who is receiving services administered through DDP. It is separate from any support plans developed through the school system; however, both plans may have similarities. The support plan lists the assessed needs and what services will be provided to both the child and his/her family to meet those needs.

Personal Support Plan (PSP) is a support plan for a person age 16 or older who is eligible to receive services administered through one of the DDP programs. The support plan lists the assessed needs and what services will be provided to the person to meet those needs.

Individual Cost Plan (ICP) is a component of a person's Support Plan if they are receiving services from one of the Waiver programs. Specific providers, services to carry out the plan, and dollars are managed. See example at the end of the Guide.

11. What are Waiver Services, Non-Waiver Services & Case Management?

DDP services are funded through two different sources: state legislature (general fund) and Federal.

Waiver programs are created through Medicaid to keep individuals with disabilities in their home communities and out of institutions, hospitals, and nursing facilities. None of these waivers is an entitlement program, so the child or adult needing this service may be placed on a wait list.

Montana's DDP Program funds services through three Medicaid waivers:

- **Children's Autism Waiver (CAW** or 0667) is for children 15 months through age 7 diagnosed with Autism Spectrum Disorder who have difficulties with adaptive behavior (e.g.: social difficulties, communication delays and/or behavior impairments).
- **Comprehensive Waiver** (sometimes referred to as "The Big Waiver" or 0208) is for individuals of any age. It provides more comprehensive supports in the community to increase and maintain independence through training, residential, recreational and vocational supports.
- **Community Supports Waiver** (or 0371) is for adults (18+) with more limited service needs. It is designed to increase and maintain independence through training, residential, recreational and vocational supports.



Children's Autism Waiver (CAW) is a Medicaid program administered by DDP for children 15 months through age 7 who are diagnosed with Autism Spectrum Disorder and have difficulties with adaptive behavior.

Comprehensive Waiver is a Medicaid program administered by DDP for any age. Provides skills (habilitation) training, residential, recreational, and vocational supports.

Community Supports Waiver is a Medicaid program administered by DDP for adults age 18 or older. Service levels are limited, but offers skills (habilitation) training, residential, recreational, and vocational supports. It's likely an eligible person will be placed on a waiting list before getting selected to receive services.



In addition to the three Medicaid waiver programs, there are two non-waiver programs which are funded and administered through DDP.

- **Part C (Infant and Toddler Program - birth to 36 months)** is a non-waiver, non-Medicaid, entitlement program which means everyone who is eligible for this program will receive services, regardless of financial or other restrictions. There is no wait list. Services may include: parent education and coaching, coordination of care, and other services based on the needs of the child and family.
- **Family Education and Support (FES - birth to age 22)** is a non-waiver, non-Medicaid program, and services are limited. It is not an entitlement program and children may be placed on a wait list. Services may include: parent education and coaching, coordination of care, assistance with transition and other services based upon the needs of the child and family.

Case management is a key service provided for eligible individuals of any age. There are two types: waiver case management for those age 0-22 who are receiving waiver services and Targeted Case Management for those 16 and older.

If you or the individual are already receiving services, you can choose which type of case management you want any time between the ages of 16-22. At 22, Targeted Case Management is the only choice. Because Targeted Case Management is an entitled service (no need for Medicaid), ALL eligible individuals age 16 or older can receive it, even individuals waiting to be selected for services (on the waitlist).



A case manager will be chosen to work with you or your family. This person is responsible for the following assistance:

- Comprehensive assessment and periodic reassessment of an individual to determine the need for any medical, educational, social or other services
- Development and periodic revision of a specific care (support) plan
- Referral to resources and related activities to support the plan
- Monitoring and follow up activities to ensure the support plan is implemented and adequately addressing the individual's needs

Part C (Infant and Toddler Program) is a Federal program (different from Waiver) administered by DDP for children birth to 36 months. This program is entitled. Eligible children and their families can get assistance with educating parents on the disability as well as coaching on how to give the best support to the child, help with coordination of their child's care, and others based on specific needs of the child and family.

Family Education and Support (FES) is a state program administered by DDP for eligible individuals from birth to age 22. Children may be placed on a waiting list to be selected for services. Assistance may include educating parents on the disability as well as coaching on how to give the best support to the child, coordination of care, assistance with transitions, and others based on specific needs of the individual and their family.

You can request a different case manager at any time by speaking to the case management agency, and then the regional office if necessary.

Your support plan will address all of the services available through these programs. Some services may be available as self-directed. Please contact your regional office for details.

12. What is Transition?

Transition means change. When it comes to DDP services, there are many changes and transitions you need to be aware of and prepare for in advance. Thankfully, there are several different people who can help you: teachers, counselors, family and friends. You'll need to work closely with your case manager to plan for these changes, especially before the ages where you or your child's eligibility ends.



Early Intervention to Special Education and other DDP services - 36 Months

It is required for families receiving Part C services that, three to six months before a child's 3rd birthday, the IFSP Team must meet to plan your child's transition from Part C (Early Intervention Program) to Part B (Special Education - School). This is also the time to ask about the possibility of transitioning to, or getting referred for, other services (DDP and others).

Children's Autism Waiver (CAW)

If your child is receiving services through the CAW waiver, you and your case manager should work together closely as your child approaches his or her 3rd year in the CAW waiver or approaches age 7 (depends on what age the child started in the waiver) to address future service needs.

Children's Services to Adult Services - Age 16

Children who are reaching the age of 16 should start planning for transition from school to the adult world. School is an entitlement service, and many of the supports provided through school will no longer be available after graduation. A transition plan is a required part of each students' school IEP (Individualized Education Program). It addressed issues like employment, education, housing, finances, and skills for independent living. Other agencies from the adult system may participate in the planning process (such as Vocational Rehabilitation). The office of Office of Public Instruction (OPI) and the Rural Institute on Disabilities have excellent resources on transition. It is important to start this process early and to never forget that employment is an expectation -- not an exception.

Transition is expected change in the future for which planning may need to occur. There are several types of transitions that can occur including but not limited to: transition into school, transition out of school, transition between services administered through DDP due to age limits and/or eligibility requirements, transition from family-focused services to individual, adult services for teenagers.

Vocational Rehabilitation (VR) is a Department of Labor program that helps people who have disabilities get and keep a job. VR helps people who have physical, mental, or emotional disabilities.

Office of Public Instruction (OPI) provides vision, advocacy, support and leadership for schools and communities to ensure that all students meet today's challenges and tomorrow's opportunities.

The University of Montana Rural Institute is a Center for Excellence in Disability Education, Research, and Service, is part of the national network of programs funded by the Federal Administration on Developmental Disabilities (ADD) committed to increasing and supporting the independence, productivity, and inclusion of persons with disabilities into the community.

Website:
<http://ruralinstitute.umt.edu/>

(Continued from Children's Services to Adult Services - Age 16)

- **Already in DDP services:**
 - ▶ Transition from high school to adult living. A Case Manager is required to be a part of this process, with adequate notice.
- **Not in DDP services:**
 - ▶ May be eligible for **Targeted Case Management (TCM)** to help during this transition from high school to adult living. Contact your regional office for more information
 - ▶ As a part of the transition plan written in the **Individualized Education Plan (IEP)** through the school district, a psychological evaluation should be included. This will assist the eligibility process for adult DDP services.
 - ▶ Adult services are not entitled programs and you may be placed on a wait list. Please call your regional office well in advance.



Remember that planning ahead is key. Don't wait until your child turns 18 to start this process, especially if you are not already on the wait list or already receiving services through DDP!

For transition tools, check out:

<http://ruralinstitute.umt.edu/transition>

13. How do I Settle Disagreements?

If you have a disagreement about anything to do with the services you or your child is receiving, first try to:

- Resolve the disagreement informally with the individual or service provider,
- Utilize the service provider's internal procedures,
- Contact your Regional Office.

Ask questions and gather as much information as possible. You have the right to good services. The best way to get good services is to educate yourself and speak up. You cannot be forced out of services because you have a disagreement with DDP or a provider.

Targeted Case Management (TCM) is offered to an eligible person age 16 or older. Targeted Case Management is entitled. For all who are eligible, the Case Manager will assess an individual to determine needs for medical, educational, social, or other services.

Individualized Education Plan (IEP) is a Support Plan developed through the school system to address educational needs and supports. The IEP is separate from a support plan developed for someone receiving services through DDP; however, they may have similarities.

14. Other Considerations for Families

Guardianship and Alternatives

It comes as a great surprise that, under Montana law, parents have no legal responsibility or control over their child after he or she reaches 18 years old. Formal **guardianship** through the court system is an option, but it isn't the only one -- there are many informal and semi-formal arrangements that can be made to meet the needs of the individual.

Contact the PLUK office at 1-800-222-7585 or e-mail info@pluk.org for more information about these options.

Guardianship applies to parents of a child who is determined to have a developmental disability and is turning or is already age 18. Guardianship is establishing a formal or semi-formal arrangement that will allow a parent to legally make life decisions for their 'adult' child.

Family Financial Planning

Planning for the economic well-being of a child with special needs is a complex issue for parents. During transition planning, parents must address financial issues with the assistance of a lawyer, accountant or banker. It is helpful for overall planning if parents have made a will. Most financial planners advise parents to avoid leaving money or assets (e.g., home, car, business) to their children with disabilities.



Any inheritance that a child might receive would have to be spent completely before that individual would be eligible for certain government benefits (waiver programs). There are several financial options for families, such as a special needs trust, where assets may be protected for the individual so they do not affect his or her government benefits. Contact the PLUK office for additional information.

Sex Education and Marriage

We know that it can be an embarrassing subject, but a young adult who is headed for a more independent life will need the information and skills to deal with sexual maturity. Very few disabilities impair sexual function, so you can assume that your child will mature sexually and need help with understanding and managing his or her sexual functions.

Families should consider how much and what kind of sex education would be useful for the child. As a parent, you may need to deal with issues of birth control. Don't forget that young adults, whether they are disabled or not, are free to marry when they have reached the legal age of 18 and have complied with state requirements (e.g., physical examination).

15. Other Resources

Addictive & Mental Disorders Division

Phone: (406) 444-3964

The mission of the Addictive and Mental Disorders Division (AMDD) of the Montana Department of Public Health and Human Services is to implement and improve an appropriate statewide system of prevention, treatment, care, and rehabilitation for Montanans with mental disorders or addictions to drugs or alcohol.

Website - <http://www.dphhs.mt.gov/amdd/>

Adult Protective Services (APS)

Toll Free: 800-551-3191 (Information Line)

APS is an agency given authority by the Montana legislature to investigate reports of abuse, neglect, and exploitation of individuals over 60 years of age or developmentally disabled and over 18 years of age. In instances of imminent danger to the individual, APS may remove the individual from danger and arrange for a safe, temporary living situation.

Website - <http://www.dphhs.mt.gov/sltc/services/APS/index.shtml>

Children's Mental Health Division

Phone: (406) 444-2995

State funded mental health services for children under age 18 are administered through the Children's Mental Health Bureau of the Health Resources Division of the Montana Department of Public Health and Human Services.

Website - <http://www.dphhs.mt.gov/mentalhealth/children>

Child Protective Services (CPS)

Hotline: 866-820-5437 (toll free, 24 hours)

Hotline: 866-341-8811 (TTY-hearing-impaired)

To protect children who have been or are at substantial risk of abuse, neglect or abandonment. We strive to assure that all children have a family who will protect them from harm. We recognize the protective capacities of families and incorporate them in assessments, decision making and actions with the goal of improving safety, permanency and well being for children.

Website - <http://www.dphhs.mt.gov/cfsd/index.shtml>

Children's Special Health Services (CSHS)

Phone: (406) 444-3622 (local)

Toll Free: 800-762-9891 (in the state of MT)

CSHS supports the development and implementation of comprehensive, culturally competent, coordinated systems of care for children and youth who have or are at risk for chronic physical, developmental, behavioral or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally.

Website - <http://www.cshs.mt.gov>

• Email - cshs@mt.gov

Developmental Disabilities Program

Phone: (406) 444-2995

DDP supports choices and opportunities for people with developmental disabilities in their communities.

Website - <http://www.dphhs.mt.gov/dsd/ddp/index.shtml>

Disability Rights Montana (DRM)

Phone: (406) 449-2344 | Toll Free: 800-245-4743

DRM protects and advocates for the human, legal, and civil rights of Montanans with disabilities while advancing dignity, quality, and self determination.

Website - <http://www.disabilityrightsmt.org>

• Email - advocate@disabilityrightsmt.org

Family Support Services Advisory Council (FSSAC)

The mission of the Family Support Services Advisory Council is to provide consumer and professional guidance to local and State agencies who plan and provide services that support families in raising their children with developmental disabilities at home within Montana's communities.

Website - <http://www.dphhs.mt.gov/fssac/>

Governor's Office

Phone: (406) 444-3111

The Governor will carry out the executive power vested by the Montana Constitution and see that the laws of the state are faithfully executed.

Website - <http://governor.mt.gov/>

Healthy Montana Kids

Phone: (406) 444-6971 | Toll Free: 877-543-7669

A free or low-cost health coverage plan. The plan provides health coverage to eligible Montana children and teenagers up to age 19. A child can qualify for HMK based on family size and income. Call to have an application sent to you, or visit the Healthy Montana Kids.

Website - <http://hmk.mt.gov/index.shtml>

• Email - hmk@mt.gov

Healthy Montana Kids Plus (HMK Plus)

This used to be called children's Medicaid, before October 1, 2009. HMK Plus is health care coverage for low-income children, ages 0-19, in Montana and is also run by DPHHS. All medically necessary services are provided to children covered by HMK Plus.

Website - <http://www.dphhs.mt.gov/programsservices/medicaid.shtml>

Independent Living Services

Promotes consumer control, peer support, self-help, self-determination, equal access, and individual and systems advocacy in order to maximize the leadership, empowerment, independence, and productivity of individuals with disabilities.

Website - <http://www.dphhs.mt.gov/vocrehab/independentlivingservices/index.shtml>

Other Resources.... Continued

Montana Council on Developmental Disabilities (MCDD)

Phone: (406) 443-4332 | Toll Free: 866-443-4332

The Montana Council on Developmental Disabilities is a citizen based advocacy group. Its members, appointed by the Governor, work to provide increased independence, integration and productivity for persons with developmental disabilities

Website - <http://www.mtcdd.org>

• **Email -** deborah@mtcdd.org | dee@mtcdd.org

MCDD Service Directory

The purpose of this directory is to provide a telephone and address list of the organizations and agencies that provide services and/or support to people in Montana with developmental disabilities

Website - <http://shortlinks.pluk.org/mcdd-directory>

Montana Comprehensive Health Association (MCHA)

Phone: 1-800-447-7828

Sometimes referred to as Montana's high-risk pool, the MCHA provides coverage of last resort and is not intended to duplicate coverage from any other source, public or private. The MCHA plans are administered by Blue Cross Blue Shield of Montana and currently provide coverage for about 3,000 Montanans.

Website - <http://www.mthealth.org/>

Montana Developmental Center (MDC)

Phone: (406) 225-4411

MDC is a residential facility for adults with a developmental disability that provides 24-hour care for those with the most severe behaviors or severe self-help deficits.

Website - <http://www.dphhs.mt.gov/dsd/institutions.shtml>

Montana Home Choice Coalition

Phone: (406) 449-3120

MHCC aims to create better community housing choices for all people with disabilities by working through a coalition of Montana citizens, advocates, providers, federal, state, and local agencies, the housing finance community, realtors, and the home-building industry.

Website - <http://www3.aware-inc.org/awareinc/montanahomechoice/main.asp>

• **Email -** montanahomechoice@awareinc.org

Montana Rotary Club

Rotary Clubs lend helping hands to people in Montana and throughout the world. Through their hard work and generous donations, they are able to help fund many projects to help benefit the community.

Website - <http://www.montanarotary.org/>

• **Email -** district5390_news@msn.com

Office of Public Assistance (OPA)

The state Department of Public Health and Human Services administers a number of programs aimed at helping low-income Montanans move out of poverty and become self-sufficient.

Website - <http://www.dphhs.mt.gov/programsservices/publicassistanceprograms.shtml>

Office of Public Instruction (OPI)

Phone: (406) 444-3095 | Toll Free: 888-231-9393

The Montana Office of Public Instruction provides vision, advocacy, support and leadership for schools and communities to ensure that all students meet today's challenges and tomorrow's opportunities..

Website - <http://opi.mt.gov/>

People First

People First Of Montana started in 1994 with the formation of local chapters across the state. In 2000, representatives of local chapters came together to form a statewide organization, the People First of Montana Senate. People First works corroboratively with other organizations as issues arise on a local or state level that negatively impact people with disabilities.

Website - <http://peoplefirstmt.org/>

Special Olympics Montana

Phone: (406) 216-5327 | Toll Free: 800-242-6876 (in MT)

Provides year-round sports training and athletic competition in a variety of Olympic-type sports for children and adults with intellectual disabilities, giving them continuing opportunities to develop physical fitness, demonstrate courage, experience joy and participate in a sharing of gifts, skills and friendship with their families, other Special Olympics athletes and the community.

Website - <http://www.somt.org/index.shtml>

• **Email -** info@somt.org

Supplemental Security Income (SSI)

Toll Free: 800-772-1213 | TTY: 800-325-0778

The SSI Program pays benefits to disabled adults who have limited income and resources.

Website - <http://www.ssa.gov/ssi>

The University of Montana Rural Institute

Phone: (406) 243-5467 | Toll Free: 800-732-0323

A Center for Excellence in Disability Education, Research, and Service, is part of the national network of programs funded by the Federal Administration on Developmental Disabilities (ADD) committed to increasing and supporting the independence, productivity, and inclusion of persons with disabilities into the community.

Website - <http://ruralinstitute.umn.edu/>

• **Email -** rural@ruralinstitute.umn.edu

Vocational Rehabilitation Services

Phone: (406) 444-2590 | Toll Free: 877-296-1197

To promote work independence for Montanans with disabilities.

Website - <http://www.dphhs.gov/dsd/mvr.shtml>

16. Glossary and Acronyms

Case Manager (CM) – May also be referred to as Targeted Case Manager (TCM) or Waiver Children's Case Management (WCCM), or just Case Manager (CM).

A CM is somebody who can assess an individual to determine needs for medical, educational, social, or other services; develops and/or revises support plan; can refer to other resources and activities to support the plan; monitors to ensure the support plan is implemented and is adequately meeting the assessed needs of the individual. Depending on the eligible person's age, this service may be entitled.

Children's Autism Waiver (CAW) – Medicaid program administered by DDP for children 15 months through age 7 who are diagnosed with Autism Spectrum Disorder and have difficulties with adaptive behavior.

Services are intense, specific, and closely monitored. This program is time-limited, and it's likely the eligible child will be on a waiting list to be selected to receive services.

Comprehensive Waiver – Medicaid program administered by DDP for any age. May be referred to as the 'Big Waiver' or 0208 Waiver.

Provides skills (habilitation) training, residential, recreational, and vocational supports. It's likely an eligible person will be placed on a waiting list before getting selected to receive services.

Community Supports Waiver - Medicaid program administered by DDP for adults age 18 or older. May be referred to as the 'CS' or 0371 Waiver.

Service levels are limited, but offers skills (habilitation) training, residential, recreational, and vocational supports. It's likely an eligible person will be placed on a waiting list before getting selected to receive services.

Department of Public Health and Human Services (DPHHS) – The Montana State agency that oversees all public health and human service programs.

Developmental Disability – A documented delay in cognitive or behavioral function compared to others in the person's age group. See page 2 for formal definition.

Developmental Disabilities Program (DDP) – The Developmental Disabilities Program is a program within the larger DPHHS agency. DDP administers, provides funding, processes payments, and monitors all the different services that are offered through DDP (see page 7).

DDP is separate from services or assistance someone might receive through school, Mental Health, Public Assistance, State Medicaid, etc.

Early Intervention Services – Federal program (different from Waiver) administered by DDP for children birth to 36 months. May be referred to as Part C, or the Infant and Toddler Program. Physicians and daycares may know or understand this program as "Child Find". This program is entitled, which means there is no wait list and every child who meets eligibility criteria will receive services.

Eligible children and their families can get assistance with educating parents on the disability as well as coaching on how to give the best support to the child, help with coordination of their child's care, and others based on specific needs of the child and family.

Entitled – Services for which there is no waiting list. People who meet eligibility requirements for 'entitled' services will receive that service right away. Examples are Part C (Early Intervention) and Targeted Case Management.

Family Education and Support (FES) – State program administered by DDP for eligible individuals from birth to age 22. Children may be placed on a waiting list to be selected for services. Assistance may include coordination of care, assistance with transitions, and others based on specific needs of the individual and their family.

Family Support Specialist (FSS) – Staff who generally provide services to children and their families. FSS staff may provide Children's Case Management, Caregiver Training Support (parent education) or BOTH to a child and family receiving waiver services. An FSS may also provide supports and coordination if a child/family is receiving Part C or FES services.

Guardianship – This applies to parents of a child who is determined to have a developmental disability and is turning or is already age 18. Guardianship is establishing a formal or semi-formal arrangement that will allow a parent to legally make life decisions for their 'adult' child.

Individual Cost Plan (ICP) – A component of a person's Support Plan if they are receiving services from one of the Waiver programs. Specific providers, services to carry out the plan, and dollars are managed.

Individual Education Plan (IEP) – A Support Plan developed through the school system to address educational needs and supports. The IEP is separate from a support plan developed for someone receiving services through DDP; however, they may have similarities.

Glossary and Acronyms.... Continued

Individual Family Service Plan (IFSP) – A Support Plan for a person through age 21 who is receiving services administered through DDP. It is separate from any support plans developed through the school system; however, both plans may have similarities. The support plans lists the assessed needs and what services will be provided to both the child and his/her family to meet those needs.

Part C Services – Federal program (different from Waiver) administered by DDP for children birth to 36 months. May be referred to as Early Intervention, or the Infant and Toddler Program.

This program is entitled, which means there is no wait list and every child who meets eligibility criteria will receive services. Eligible children and their families can get assistance with educating parents on the disability, as well as coaching on how to give the best support to the child, help with coordination of their child's care, and more based on specific needs of the child and family.

Personal Insurance (Autism) – Broadly speaking, the Montana Autism Reform Law requires many private insurers to begin covering the costs of diagnostic assessments for autism and of treatments for individuals with autism

1. \$50,000 per year for a child 8 years or younger
2. \$20,000 per year for a child 9 years through 18

The specific terms and provisions of this law are described in more detail at: <http://www.pluk.org/autismvotes>

Personal Support Plan (PSP) – A support plan for a person age 16 or older who is eligible to receive services administered through one of the DDP waiver programs. The support plan lists the assessed needs and what services will be provided to the person to meet those needs.

Targeted Case Management (TCM) – May also be referred to as just Case Management (CM). TCM is offered to an eligible person age 16 or older.

Targeted Case Management is entitled, which means a person meeting eligibility requirements will receive CM services, even if they are not getting any other services administered through the Developmental Disabilities Program. For all who are eligible, the Case Manager will assess an individual to determine needs for medical, educational, social, or other services.

For those who are selected to receive other DDP services, the CM develops and/or revises support plan; can refer to other resources and activities to support the plan; monitors to ensure the support plan is implemented and is adequately meeting the assessed needs of the individual.

Supplemental Security Income (SSI) – Supplemental Security Income (SSI) is a Federal income supplement program funded by general tax revenues (not Social Security taxes). It is designed to help aged, blind, and disabled people who have little or no income; and provides cash to meet basic needs for food, clothing, and shelter.

Special Education Services – Children and youth (ages 3-21) receive special education and related services under the federal Individuals with Disabilities Education Act (Part B). The purpose is to ensure that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living.

Special Needs Trust – Enables a person with a physical or mental disability, or an individual with a chronic or acquired illness, to have, held in Trust for his or her benefit, an unlimited amount of assets. In a properly-drafted Supplemental Needs Trust, those assets are not considered countable assets for purposes of qualification for certain governmental benefits.

Transition – An expected change in the future for which planning may be necessary. There are several types of transitions that can occur including, but not limited to: transition into school, transition out of school, transition between services administered through DDP due to age limits and/or eligibility requirements, transition from family-focused services to individual, adult services for teenagers.

Waiver Children's Case Management (WCCM) – May also be referred to as Case Management (CM). The staff that perform Children's Case Management is usually referred to as an FSS, so this service is associated with an FSS staff, and may even be called FSS.

WCCM is offered to a person receiving services through one of the Waiver programs, up to age 22 if desired. A CM is somebody who can assess an individual to determine needs for medical, educational, social, or other services; develops and/or revises support plan; can refer to other resources and activities to support the plan; monitors to ensure the support plan is implemented and is adequately meeting the assessed needs of the individual.

Guide to Success: Navigating Montana's Developmental Disabilities Program

A GUIDE TO UNDERSTANDING THE DEVELOPMENTAL DISABILITY SERVICES SYSTEM.

"Wow, this is great. Now I know why those people were coming to my house." (Parent)

"This is going to be very useful for families like mine." (Parent)

"I like everything about the guide and appreciate the updated information, the concise delivery, and the support for families and parents." (Professional)

"This guide is going to make my life easier and save some time chasing down information to provide to families. It answers a lot of the questions I've had, too. Thanks for doing this." (Service Provider)

The "Guide to Success: Navigating Montana's Developmental Disabilities Program" was developed through a unique collaboration between parents of children who benefit from services provided through Montana's Developmental Disabilities Program and the State of Montana Developmental Disabilities Program office.

The goal was to create a handbook that was written in a way that would be understandable to any parent, self-advocate, or community member and would teach the reader about the program as a whole, how it works, how it is funded, and who it serves.

We hope this information will assist in the process of finding the help and services you need.

The Developmental Disabilities Program provides oversight and funding for the service system that supports individuals with developmental disabilities and their families. They currently have an annual budget of \$114 million, serve over 4,000 individuals and work with over 60 service providers across Montana. The mission of DDP is to ensure choices and opportunities for people with developmental disabilities in their communities.

PLUK is a network of over 30,000 families of children with special needs in Montana dedicated to providing training, information, and support at no cost to individuals of any age, their family members, and the dedicated educators, professionals, and others that serve them. We become as well informed as possible in the fields of education, medicine, law, human services, rehabilitation, and technology to help empower individuals and families to make informed decisions about their lives and futures.

PLUK
516 N 32nd St.
Billings MT 59101
406-255-0540
<http://www.pluk.org>

Developmental Disabilities Program
DPHHS Building 111 Sanders
Helena MT 59620
406-444-2995
<http://www.dphhs.mt.gov/dsd/ddp/>



PLUK services are available throughout Montana and are free to individuals with special needs and their families.